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ABSTRACT

Intended as a training manual for medical, educational, and institutional staff who work with disabled adolescents and adults, the booklet seeks to provide basic knowledge and dispel common myths surrounding sexuality and disability. Translated from Swedish, chapter titles and selected subtopics are as follows: (1) "Sexuality and Disability: A Matter that Concerns All of Us" (distinction between the concepts of disability and handicap; reactions of able-bodied persons to questions and problems concerning sexuality); (2) "Start Talking with Each Other" (staff evasiveness in dealing with sexual problems, the role of self-esteem in establishing personal relationships, attitude change, providing information in support of positive sexual identity for disabled persons); (3) "Sex Roles--Threat or Possibility" (developing alternatives to compensate for a disability, providing realistic information to the mass media); (4) "Sexuality and Sexual Interaction" (sexual rights; changing or improving sexual interactions; sexual aids and sexual rehabilitation); (5) "Reducing Dependence" (adolescent liberation and sexual knowledge; staff attitudes and professional responsibility; including sexuality in rehabilitation; starting study circles and discussion groups for staff, disabled persons, and their families). (JW)

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SEXUALITY AND DISABILITY

- a Matter that Concerns All of Us

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SEXUALITY AND DISABILITY

- a Matter that Concerns All of Us

EC 192431

The Swedish Institute for the Handicapped is working with investigations, research and devolpment, testing, education and information about technical aids, housing and environmental planning for persons with various kinds of disabilities. One of the projects: Relationship and Sexuality. The Institute is financed by the Government and the Federation of Swedish County Councils.

Manuscript Inger Nordqvist
Illustrations Cinna Gross
Pedagogical preparation and production Liber Utbildningskonsult AB
Translation Richard Nord, AB Exportspråk

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Foreword

Sexuality and disability—a matter that concerns all of us! By giving this title to our book, we wish to indicate how important this subject is—for all of us. We invite each and every one of you to give careful thought to and discuss your attitudes and values concerning sex and intimate interpersonal relationships. At the same time, we wish to give a greater practical content and meaning to the concept of sexuality for people with disabilities.

Misconceptions concerning sexuality and disability are not uncommon. With this book, we hope to be able to dispel many myths while at the same time providing some basic knowledge to make it easier to tackle these questions and start discussions and instruction.

The goal has been to put together a simple, general and easy-to-comprehend training manual that can be used in staff training courses, adult study circles, seminars and other educational settings.

The target groups are nursing teachers, student nurses, teachers and students at other schools that have contacts with disabled persons, staff at various kinds of institutions of care, people with disabilities and their families and loved ones etc.

If you have any comments, helpful hints, questions or ideas, write to Inger Nordqvist at the Swedish Institute for the Handicapped, Box 303, S-161 26 Bromma, Sweden.

Sexuality and Disability –a Matter that Concerns All of Us

"When I attended a course on handicaps a while back, I found that the questions concerned merely technical problems. No one dared to talk about feelings. It is important to affirm your sex and your sexuality and to like your whole self."

(Lollo Jansson, visually impaired, from Information om rehabilitering ("Information on Rehabilitation") 7/8 1980.)

When we talk about handicaps and disabilities, we generally mean practical matters—access to public transportation, toilets, cinemas and counselling services. Only rarely does the discussion turn to feelings, and least of all sexual feelings and matters pertaining to loving and intimate interpersonal relationships.

For people who are unsure of their own feelings and others', it is easier to discuss matters such as technical aids and access to transportation. Then we are talking about concrete things that can be measured in different ways. Feelings and attitudes are less tangible and more individual—and this is even more true of sexual feelings and attitudes to various forms of intimacy and sexuality.

This book is a manual intended to provide some basic knowledge concerning attitudes, sexuality and disability. It describes different ways to deal with these questions on an individual and group basis. We hope that it will provide some pointers on how to prevent, deal with and solve problems that can arise in the area of sexuality and intimate relationships for people with disabilities.

The goals of the manual are to

- ▷ influence attitudes and values concerning sexuality and disability and lift the taboos (something forbidden, not to be touched or spoken of) surrounding the subject of sexuality
- ▷ dispel sexual myths (imaginery concept, handed down from olden time) and make it easier for people to discuss sexuality and disability
- ▷ offer insights and indicate ways to facilitate sexual expression and intimate relationships for people with disabilities
- ▷ create such attitudes that people with disabilities are treated with respect and that able-bodied people respect and trust the wishes and feelings of disabled people

By "disability" is meant in this book all types of functional impairments (mobility impairments, visual impairments, hearing damage, mental retardation, medical disabilities etc). The reason we lump all of these different disabilities together is that we have found that people who are disabled in various ways from an early age all receive equally inadequate information on matters related to their sexual lives from professionals, staff, parents and schools. Similarly, a common experience of people who have got losses of vision, hearing, mobility etc in adult age or been affected by medical disabilities such as psoriasis, is that they are treated differently after the loss. As if they had suddenly become quite different people than before.

In contrast to a disability, a "handicap" exists in a relationship between an individual and the environment in which he or she is active. In other words, a person with a disability can be more or less handicapped, both in his working life and in his leisure time, depending on the environment. Handicaps can be alleviated considerably by adapting society to meet the needs of its disabled members. (Despite this strict and important difference between the meanings of the words "disability" and "handicap", the two terms are used interchangeably in general conver-

sation and are also used interchangeably in this manual.) This adaptation of society involves removing both psychological barriers—fear, popular ideals and prejudices inside us that stand in the way of interhuman encounters—and physical barriers, i e multiple-bed rooms instead of single rooms at institutions, stairways and narrow doors that restrict access etc.

As staff and parents, family members and individuals with disabilities, we are likely to react with fear and insecurity when we encounter questions and problems concerned with sexuality. In the first place, many of us are poorly informed concerning sexual opportunities, and in the second place we are influenced by illusions, myths and taboos concerning sexuality, whether we are handicapped or not. All of this we have inherited from parents and society. Intellectually, our lack of knowledge makes it difficult for us to solve problems and answer questions. Emotionally, we believe that our own private picture of sexual reality (what we believe, hope, perceive and desire sexually) is also shared by others, because we have had so few opportunities to discuss this subject with each other and compare notes. The result is that we have a tendency to think for others and interpret what others want, especially if by "others" we mean people with disabilities. But no one can know what anyone else thinks or wants without asking or discussing with that person. This applies not only to a staff-patient relationship but just as much to any sexual relationship. It is, indeed, a matter that concerns all of us!

Starting to come to grips with these matters requires courage—the courage to dare. Just as in other areas, training is required in order to achieve skill and a sense of security.

Topic for Discussion

Would you like to be treated differently if you were disabled in an accident?

Start Talking with Each Other

"First I was extremely embarrassed about discussing the subject with my classmates. I was the only one who was handicapped. But there was a visually impaired pupil and a hearing-impaired pupil in other grades at the school. Writing the essay helped a lot. I am more open now and it is easier for me to talk about sex."

(Äwah Lundell, who has rheumatism, wrote an essay entitled "The right of the handicapped to love".)

The greatest threat to opportunities for disabled people to express themselves sexually comes not from the disabilities in themselves but rather from professionals and staff. As staff, we can avoid or refuse to answer questions and obstruct information, due largely to our own fear of becoming involved in embarrassing or unpleasant situations.

It is not unusual for different professional groups to pass the buck to each other. If we think it is difficult to talk about sex, it is easy to refer the matter to someone else. If we also feel insecure in the face of the disability itself, this can make it even more difficult for us to talk about sexual matters, whether we are professionals or parents.

What are the consequences of this?

If a man or a woman with a disability encounters this kind of evasiveness or insecurity on the subject of sexuality and intimate relationships, the individual will also feel insecure and may suddenly start asking him/herself "Do I have any value as a man/woman to other people when the staff here act as if I shouldn't expect anything? Maybe there's no use in me even trying to find someone? I don't seem to count!" The contrast to the way in which information is given in a clear and confident manner on other subjects (diet, medicines, exercise) makes this reticence regarding sexuality even more pronounced.

A woman who had had a colostomy (with a bag on her stomach to collect the contents of her bowels) said, "I have been waiting and waiting for someone to tell me what having a colostomy means for my sexual life. What can I do? What should I avoid? I want some advice!" She also said, "It's very difficult to ask the right questions, since I don't know enough about anatomy and don't have the faintest notion of how my disability might affect my sexual life."

It is easier for us to find solutions to problems together with our fellow staff members or together with the patient, than trying to find our way on our own.

At hospitals or institutions where information on sexuality and intimate relationships is included naturally, it is also easier for the patients or residents, through discussions, to get different perspectives on their lives—which in turn makes it easier for them to believe in themselves.

Believing in Oneself

How our emotional relations to others develop depends to a large degree on ourselves. No one else can do this for us. But others can help to give us a foundation of security and self-esteem by dealing with us positively and fairly. Sometimes we may feel obliged to love someone. Sometimes we may also confuse friendliness with love. But no one can make anyone love someone else. Love is a feeling that must come from within.

It sometimes happens that female staff members unwittingly play out their sexuality against a male patient whom they regard as "harmless". They tease him sexually. Either they arouse false hopes, or the man understands how little the woman counts him as a man. Either way, his self-esteem suffers. This doesn't mean that we staff have to suppress our male or female identity entirely, it just means that we have to accept responsibility for how we act towards others. We can deal with each other as human beings and with respect for each others' roles as men or women, even at a hospital.

If you meet such respect, it is easier to respect and like yourself. If you like yourself, it makes it easier, despite a severe handicap, to take the initiative to develop relationships with other people. It is also important to learn how to tell when another person is attracted to you, both sexually and in other ways.

A young man with muscular dystrophy described how, after having moved away from home, he realized too late that a number of girls had been interested in him. He hadn't believed in his own powers of attraction, and he realized now that he had missed many chances. The reason why he realized it now was that his self-confidence had grown when he saw that he could compete with other men for girls (he was now engaged).

A person with a visual impairment may meet, move together with or marry someone else who is visually impaired. Another disabled person may meet an able-bodied partner. Some people—disabled or able-bodied—live the greater part or all of their lives without any partner. The reasons may be many. Perhaps they have had too few opportunities to get out, haven't dared to look for or haven't found the person they were looking for. Or perhaps they themselves did not wish to become too deeply involved, with all that entails of having to give of themselves and receive from another.

While we mustn't ignore the fact that many people with disabilities have difficulty in meeting other people and making new acquaintances, neither must we get stuck in the belief that all problems are due to the disability. The following example illustrates how it is possible not to allow a disability to limit one's contacts. A very disabled man, a spastic with severe speech difficulties who could not control his saliva, was looking for a woman for a long-term relationship. He advertised in a newspaper and got a reply from a slightly disabled woman. They became engaged and now live together.

What can practically be done to help in the individual case is to sit down together and try to find out what lies behind the contact problems. Is it practical things, or is it social awkwardness? Social awkwardness may be due to a lack of the basic social skills. Here, role playing can be used to train such skills.

Meeting new people, making new acquaintances and being able to attract someone we like, is something we all think about and sometimes worry about in different periods of our lives. Deep down inside, we are all a little insecure about other people's opinions of us. We all want to be popular and well-liked.

Topics for Discussion

Problems of loneliness and anonymity are mentioned in many contexts—what do you think they stem from? What is the situation like in society? What is the situation like here? How does it feel? What qualities are important for establishing and sustaining an emotional relationship?

Are You Clear about Your Own Attitude?

It happens quite often that doctors and other health-care staff do not have the knowledge that is required to provide information on sexual matters. It is not self-evident to everyone that a severely paralyzed woman can have a functioning sexual life. One midwife thought, for example, that women who use a wheelchair are unable to give birth to children. She wasn't aware that pregnancy and childbirth are very seldom affected by physical disability. On the other hand, the weight of the foetus can be difficult to bear for a person who walks with crutches and/or has a weak back.

A Swedish study found that it was not the severity of the disability that determined whether a person with a disability felt that he/she had a satisfactory sexual life or not. It was instead a question of how much importance the individual allows the disability to assume in his/her contacts with other people and what content he/she gives to the word "sexuality". Sexuality can, for example, find expression not only through sexual intercourse, but also just as fully and completely through nearness to the person one loves, in glances, words and through skin contact and caresses. The results of numerous other studies point in the same direction.

We also know too little about how our bodies and emotions interact. This ignorance is reinforced by prejudices

and the attitude of our age that a perfect body is a guarantee of being loved. Some able-bodied people with a perfect body but with a far-from-perfect sex life may feel threatened and unwilling to accept the fact that men and women with disabilities may have a better sex life than they do. If they accept this, then their cherished attitude of "feeling sorry for" or "taking care of" disabled people may fall apart.

Quite a few changes have taken place over the past ten years, but it is still surprising how little people know. Disability and sex is no longer such a taboo subject. But it arouses personal and subconscious reactions in many of us.

Topics for Discussion

Why do you think people feel uneasy when they discuss or hear the term sexuality?

How can we achieve greater frankness and realism in our discussions of sexuality and intimate relations?

Changing One's Opinion

Nor are our attitudes towards disabled persons always positive. There are people who are negative, but whose opinions can be changed, if there is a chance to probe more deeply into why they think and act as they do.

Most attitudes arise in various group contacts. Our attitudes are formed and confirmed in interaction with parents, friends and colleagues. Inexperience and ignorance may also play a role.

In order to change a negative attitude, we must first determine what aspects of the attitude need to be worked on. Is the underlying factor ignorance or something our parents may have said about handicap, or does it lie in our own experiences? Experts say that it is often not enough just to inform. If attitudes and behaviour are to be changed on the practical plane, it is necessary for able-bodied and disabled people to meet voluntarily in order to work together towards a common goal.

Your Anxiety and Mine

"The course has given me a little more courage to dare to speak of these things with people in general (which is much more difficult than with patients or clients, I think—we are usually much too inhibited by our upbringing) instead of waiting for other people to bring up the subject. The result was better than I dared to hope before I started daring!"

(From an evaluation of a course on sexuality and disability.)

Two things are important:

- We mustn't think that we are arousing anxiety in adults or young people with disabilities by discussing sexuality, informing them of what sexual opportunities they have and what difficulties they may run into. On the other hand, we ourselves may become anxious if we think we have to protect people with disabilities.

- We mustn't assume that our own situation, our own sexual life, our own desires and opinions are a model for others.

What is important is to give support and information to the individual in question as to what he or she *can* do so that she really believes it. This is a way to develop a feeling of positive sexual identity, which is important to everyone. Without free and open discussion, unreal fantasies and anxiety will have free play.

Topics for Discussion

What is sexuality for you (feelings, sex drive, man, woman, reproduction, nearness, consideration, desire)? Choose among these and other concepts.

What do you think about masturbation/provide sexual excitement/release by own stimulation of the genitals/, petting, sexual intercourse in different kinds of relationships (steady company, casual relationships, within marriage, outside of marriage)?

Are your attitudes positive, negative or neutral?

Have opinions (yours and society's) changed since you were a teenager? If so, how and why?

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What factors influence our opinions on intimate relationships and sexuality?

Many different factors are involved here. What is most important is that we should be aware of our own opinions and the feelings underlying them. Only then will we be able to modify our behaviour so that we don't needlessly offend and ridicule other people's attitudes towards their own sexuality. Among the factors that influence our attitudes is how and whether our parents showed tenderness to each other and to us, the conditions under which we were brought up, information through friends, teachers, parents, the mass media, the values of society and our own sexual experiences (positive and negative). Since our opinions can be changed, what we learn through experience can counteract an emotionally deprived upbringing. Most of us have been brought up with the myth of the perfect marriage, "and they lived happily ever after". Later on, many girls have been exposed to ideas of romantic love and many boys have been subjected to pressures to have an active, performance-oriented sex life. Both girls and boys have their dreams and ideals. As adults, they must meet each other in reality. Whether or not they succeed depends to a great deal on how close to reality their dreams are. If the gap is too large, disappointment is inevitable.

Other factors that influence our opinions are

- ▷ whether we obtain new knowledge through contacts with other people or by other means
- ▷ how we take in such knowledge during our adult lives
- ▷ what we do with this new knowledge. Do we refuse to listen, hear or see, or do we use knowledge to grow even if it means changing our opinions and perhaps our way of living?

Sex Roles–Threat or Possibility

"Most of us are born into thinking in terms of sex roles. Just consider the different games boys and girls play. Then what happens when someone becomes disabled? We think it's natural that a woman takes care of her husband, but when a man cares for the wife, people say: 'Oh, how nice of him to take care of his wife."

"Girls are allowed to cry. So it is acceptable for disabled girls to cry if they are unhappy. Guys take a drink instead."

How you relate to your own role as a man or a woman can further influence your thinking.

"Did your father build this house?"
"No, my mother did."
"But your father painted the house?"
"No, mother did that too."
"But your father must drive the car anyway?"
"No, mother does that too."
"Does your father clean the house then?"
"No, mother does that."
"Doesn't your father do anything?"
"Yes, he's terrific at telling bedtime stories."

(About a visually impaired father. From Handikappsamverkan 1975:1/2.)

Some able-bodied men who have learned that the most important thing in life is achievement and performance and who have regarded it as shameful to fail in their sex life, find the greatest difficulty in affirming the sexuality of men with disabilities. They think that if a man can't achieve intercourse or have an orgasm every time, he is a failure sexually. This is just another myth, since the emotional side of a sexual interaction is a part of the interplay

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between body and mind. Emotions can enhance pleasure. If the emotions are lacking, they can cause psychological impotence (inability to respond sexually) in the man and the woman. It is difficult for a man who identifies strongly with his sex role to suddenly find himself disabled. It demands a great deal of friends, family, sexual partner and staff to build up his self-confidence and self-esteem and to alter previous values. An example of the opposite is a married 60-year-old man with M.S. (multiple sclerosis) who has been unable to have an erection (hardening and swelling of the penis or clitoris) for ten years. "Actually, I think we have a rather good sex life. I call it intercourse, since we have closeness and skin contact and I satisfy my wife when she wants it. I enjoy that."

New Activities and Roles Develop

But a disability can even have a "relieving" effect. The man is under less pressure to have a career and suddenly has an opportunity to devote himself to things that are important to him—even things regarded as "unmasculine".

A man who became unemployed after an accident related with great joy that he had received an electric wheelchair, which had changed his life. Now he could go along and watch his son play football in the daytime. For him, this was the greatest thing about the new wheelchair.

Developing new activities, which also provide new opportunities for meeting people, is one way to deal with the activity losses that occur as it becomes more and more difficult to get about. A 30-year-old woman with rheumatism drew up two graphs over a 10-year period, one with losses and one with gains. When she had to give up basketball, jazz ballet and teaching gymnastics, she instead became interested in reading, writing poetry, drawing and batique.

It is important to all of us to be aware of the prevailing taboos, myths and sex role conceptions that exist and

become mixed into contexts with sex and disability. Believing that only women are allowed to have feelings and that men should be strong are sex role prejudices that merely create misunderstanding and give distorted pictures of reality.

If a disability occurs (in this setting), such prejudices become an additional burden in sexual relations. One example may be that an able-bodied woman must become more active sexually because her partner has difficulty moving during intercourse or requires more intensive stimulation to get an erection. If she has been brought up to suppress her sexuality and be passive, she will require support to change her values so that she and her partner can have a more pleasant time together. An able-bodied man also needs information on how he may have to prolong the sexual foreplay if his wife, girlfriend, partner etc requires more stimulation as a result of a nerve injury.

If one partner is disabled, it is necessary to talk a great deal before making love concerning what feels best, how the partner wants to be lifted etc.

Really taking the time to listen to each other and ask what the other person wants can contribute towards getting away from the performance demands that tradition and society place upon us.

What else can "society" do to facilitate sexuality for disabled persons and their loved ones?

Provide realistic accounts of sexuality in general in the mass media to counteract romantic and performance-oriented myths.

- ▷ Dedramatize by spreading widely knowledge on the opportunities available for disabled persons to lead a satisfactory sex life
- ▷ Hold open houses for the public, friends and family at hospitals, institutions, handicap-organizations
- ▷ Stop glorifying "clever" disabled people and provide factual information concerning handicap in the mass media
- ▷ Answer children who ask about disabled people they see and don't hush them up. We will otherwise lay the foundation for attitudes that disabilities are something shameful which one mustn't talk about
- ▷ Have journalists in the mass media work as trainees at student homes, schools, rehabilitation institutes, handicap-organizations etc to provide them with a real background.
- ▷ Try sitting in a wheelchair for one day and being disabled—visit shops, a post office, a cinema etc or try to telephone somewhere, take a cab and experience the attitude of others

- ▷ Work to eliminate myths such as "There is something strange about someone who marries a disabled person" or about single mothers—"How can she, who has a handicapped boy/girl, go out and have a good time! She should be ashamed!" or "How can he leave her—she's handicapped!"
- ▷ Show tolerance and understanding for the fact that we are all different

Topics for Discussion

When did you discover that boys and girls are created differently? What did your parents say? How did you talk about sex at home? How did you talk about sex in school? What were you ignorant about?

What do you think most people think?

- ○ the man should be the most active partner in sex
- ○ the woman should be the most active partner in sex

How is it in practice?

Would the answers be different if one partner had a disability?

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Sexuality and Sexual Interaction

Sexuality is something we have from the start. Whether we are going to become men or women is decided at the instant of conception, and the genitals develop during the life of the foetus. We develop physically during puberty, sex hormones start to be secreted and our sexual needs become stronger. This is the biological part. The emotional part of our sexual development has its basis in our childhood, our upbringing to become men or women, but also in how positively we accept the gender to which we belong. Sexuality includes our feelings and opinions as well as how we deal with them to go on to act sexually.

Our sexuality contains so many different components that it can't be suppressed or disappear just because other people pretend that it doesn't exist.

Everyone Can Have a Sex Life

"All human beings have sexual rights and everyone should have access to sexual counselling and information so that they can live the sex life they want." These lines were adopted at a world congress on disability in 1980.

A sex life is more than just a sexual relationship with another person. It can also find expression in the projection of one's masculinity or femininity in contacts with other people in different ways—in looks, words, manner of dressing etc. Or it can find its expression through masturbation.

We all need love. It is something positive that is not reserved for young, beautiful people, as advertisements

would lead us to think. The elderly also have love needs and sexual needs, since it is very difficult to separate sexuality from love. Would we ourselves put up with being separated from our spouses if we ended up in a home for the aged or on a long-term care ward? The need to feel and give warmth, nearness, love and intimacy has nothing to do with age. An active sexual life can continue up to and over the age of 75–80 and can help to delay certain ageing symptoms.

Those who don't believe they can have a sex life are either poorly informed or have had difficulties in assimilating information due to a negative influence from their environment, from myths and from their own and others' values. This is an unsatisfactory state of affairs which we are all obliged to try to rectify.

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Topics for Discussion

A person with a disability may constantly require help in different ways. Does the need for help influence other people's attitude towards his/her sexuality?

Where does integrity come in?

Making Love Is More than Intercourse

Sexuality is so much more than just sexual intercourse, or coitus. The idea that only sexual intercourse is the "real thing" stems from the fact that we associate sexuality with reproduction. This attitude has its roots far back in time, when people thought that the sole purpose of sexual intercourse was to have children and not to derive pleasure from each other.

Sexual intercourse can be difficult, painful or even impossible for some people with physical disabilities or medical handicaps such as severe incontinence (difficulty in controlling bladder or bowel functions). The difficulty may stem from the fact that the woman may not be able to part her legs, that the man is unable to sustain an erection for an adequate length of time or that it simply hurts too much (if the woman's mucous membranes are too tender). But there are other ways that can give complete satisfaction for both partners. Caressing each other and using hands and mouth to stimulate each other's genitals is something some couples practice instead of intercourse. Others use it as a complement.

If a person doesn't have any sense of feeling at all in the lower half of his body, the area just above the injury may become much more sensitive to touch than before. There are many areas on the body besides the genitals that are erotically sensitive, for example the mouth, ear lobes, shoulders and nipples on both men and women, something we seldom make use of.

Some Examples

A young man with paralysis of the legs and a weak back lies on his back during intercourse. He has difficulty getting an erection but has solved it by means of petting and communication with his partner and has bought a book about coital positions. He cannot get an erection when he masturbates (due to the injury), but only when his partner touches his penis.

A couple that lives together, both in wheelchairs, use the side position. His tactile sense is impaired and it takes a longer time for him to reach orgasm. She likes the back position best, but for his sake she uses the side position, and through petting she achieves orgasm before they have intercourse. The only difficulty they experience is that they have fewer choices of positions and greater difficulty in having spontaneous intercourse, since they have to plan it in advance. Both say that they didn't think they had intercourse as often as able-bodied couples (once a week or more). In discussions with friends, they were pleased to hear that their friends had intercourse less often despite the fact that they were able-bodied.

A married woman suffering from allergy often has to interrupt intercourse with her husband due to allergic reactions, chest congestion and sneezing and engages in petting instead. She has solved some problems by decontaminating the bedroom. There are no carpets there and the curtains are made of synthetic/cotton and are laundered once a week.

Topics for Discussion

Do you know of any similar cases?

What do you think about pornography for single persons with disabilities who have difficulties in achieving sexual satisfaction and need extra stimulation during masturbation?

What is pornography and what is not pornography for you?

Which coital positions are you familiar with and able to give advice on?

How would you react if someone asked you for help with masturbation?

If you have never discussed sexuality where you work, it may make you very uneasy and anxious. You may not know what your colleagues think and you may not dare help. Some people don't mind at all helping — or making it easier for the person to masturbate, for example by putting a handle on a vibrator, arranging cushions behind the person's back for support, leaving the person alone on a bidet or making sure that the toilet seat is provided with a vaginal douche that can be used as an aid to masturbate.

It is very important that the staff members, who are willing and able to make it easier for a person with a disability to masturbate, are permitted to do so without being stopped by colleagues who are unable or unwilling themselves. We must accept both those who wish to help and those who are unable or unwilling.

What is most important is to discuss the matter among your colleagues and not to freeze out the person who wishes to offer assistance. Consider questions such as: What alternatives for sexual activity exist for the person who is asking? None at all? What are the consequences of that?

Changing or Improving a Sexual Interaction

- ▷ practice talking with your partner about what feels good, where and how
- ▷ realize that using a lubricant can facilitate intercourse and prevent irritation if the woman does not have sufficient vaginal secretion
- ▷ make greater use of your erogenous zones (areas of the body particularly sensitive to sexual stimulation) to increase their responsiveness
- ▷ realize that you don't have to have intercourse to satisfy each other, since there are other ways—mouth, tongue, hands
- ▷ change coital position so that the person who has the greatest difficulty moving is on the bottom, or on the side
- ▷ be the person who is least active in your sexual life (if the man has a disability, the woman must train herself to become more active)
- ▷ realize that it is possible to have intercourse without an erection (if that is what the couple wants), either by having the woman, in the superior or squatting position, pull in the penis by contracting the vaginal sphincter muscle and using vaginal lubricant or by having the man using a penis stiffener—see sexual aids
- ▷ find out how to tape a catheter along the penis on the man or up on the stomach on the woman, or obtain instructions on how to take the catheter out and put it in again
- ▷ realize that some men with a spinal injury, urostomy (the urine is conducted to a bag on the stomach) etc can have an orgasm without having an ejaculation
- ▷ realize that an orgasm can also be experienced solely emotionally—which is why many men and women with nerve injuries experience a "mental orgasm".

Sexual Aids and Sexual Rehabilitation

Aids for enhancing the sexual pleasure of the able-bodied have been used for more than 2000 years. For couples where one partner has a tactile or nerve injury, sexual aids can be used to come close to the pleasure experienced by the able-bodied. As in the case of all forms of sexual expression, the couple themselves must decide what is best for them. It is also important for a person's self-esteem to be aware of his sexual capabilities. Those who snort derisively and say that technique isn't important in a sexual relationship are usually able-bodied, have an undamaged nerve system and function quite normally physiologically.

Artificial aids to sexual fulfilment can be just as important to disabled men and women as hearing aids, dental plates and wheelchairs. One reason for using aids is that more intensive sexual stimulation may be required in order to prepare the body for intercourse or orgasm. And if a person loses his or her lifelong companion, the burden will be even greater to bear if he or she has to face a life of sexual abstinence as well.

The most commonly used aids are:

- *electric vibrators*: usually penile-shaped and batterypowered, sometimes with a tip for stimulating the glans on the tip of the penis; otherwise they are used to stimulate the woman's clitoris

- *pubic ring*: a doughnut-shaped ring of soft rubber that is pulled up over the base of the penis so that the blood which has rushed inte the penis when it becomes erected stays there—it is used for at most 20 minutes
- *penis stiffener*: a condom-like sheath that is slipped over the penis, also available with built-in vibrator

These articles can only be obtained from mail order firms or sex shops. Our puritanical heritage is evident here as well.

How Are They Used?

Vibrators; men and women:

- to stimulate whatever feeling remains or determine where there is feeling
- to get more intensive pleasure than can be obtained from the hand alone (pair relationships)
- to satisfy an able-bodied partner
- as a means of masturbation
- as a complement to another activity aimed at finding sensitive areas on the body

Pubic ring; men:

- to maintain an erection

Penis stiffener; men:

- as a means of masturbation (with built-in vibrator) or to permit coitus with a limp penis, or without a penis, for example after cancer surgery

Other aids are:

- cushions to provide support or weight on arms and legs for people with involuntary movements
- less transparent bags to wear over the ostomy during sexual activities
- a shower for masturbation and as a complement to a couple's sex life

How can we make it easier to discuss the problems of sexuality with "newly handicapped" people, with or without partners, in order to help them give their sex life a chance?

If the disabled person has a partner, he or she should be included in the discussion at as early a point as possible. Discuss with both parties, or with the single disabled person, the fact that many people wonder about their sex life after an injury and try to find out what they believe, have heard or read. Straighten out any misunderstandings. See the pages about myths etc. Use former patients as a resource and bring the parties together. Lend and give tips about pamphlets and other books on the subject. Discuss how other people in the same situation are functioning. Make it clear that it is okay to ask about sex and don't use any words without making sure that they have the same meaning for all of you. Changing one's sexual ways takes time, and success won't come the first time around.

At the end of this manual you can find a bibliography on sexuality in general and on sexuality in the context of different disabilities. For further advice contact the librarian, the family planning organization, the Human Sexuality Program at the University, or the Faculty of Medicine.

Reducing Dependence

No one can have a sex life without other people. A person with a disability is perhaps even more dependent on positive attitudes on the part of the people who are closest to him/her, i e parents, other family members and close friends, and staff.

For a young person who has few contacts with other people, dependence on parents can be strong. The parents must be clear in their own minds about their attitudes towards sex in order to be able to talk about it with their child. They must find out what particular possibilities are open to their child in order to be able to give positive support and talk about the future. One way is to ask all medical staff of any kind who have any contact with the child, for example doctors and social workers, in order to emphasize how important this is. If it is difficult to obtain any information, the parents can also ask someone else to ask for them.

Adolescent Liberation and Sexual Knowledge

We can start by noting the following:

- Many adolescents with disabilities are very poorly informed on sexual matters
- Adolescents with disabilities have a great need to show and talk about their feelings and to be accepted as young people with a sexual potential just like able-bodied young people

- Responsibility for seeing to it that adolescents with disabilities are given an opportunity to have as "normal" a sexual life as possible also rests with parents and other close family members and friends as well as professional staff. The staff's responsibility is to make sure that every disabled adolescent is able to choose freely with whom he/she would like to discuss these matters.

Parents of adolescents with disabilities must receive support and encouragement to help them go through the process of liberation that is necessary for the child. This process can sometimes be very difficult, both for the parents and the child. Guilt feelings are often a part of the picture. The child is entitled to his/her own life, and to live out his/her feelings, sexual and emotional, and has other needs than just help to get dressed etc. This can be

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difficult for parents to realize if they have not received sufficient information. In order to aid and facilitate the process of liberation, information on the normal development of children and adolescents should be given to both parents and staff.

Most adolescents who are mentally retarded go through puberty in the same way as other adolescents but have greater difficulty understanding what is happening to them, to their bodies and to their emotions. And spontaneously they don't ask enough questions. Here it is even more important that the initiative comes from an adult.

Sex education must often be explicit and go into concrete details. Through discussions or role-playing, the following subjects can be probed:

- how to strike up an acquaintance with someone you like
- how and where to masturbate
- how to put on a condom
- how to acquire and use oral contraceptives (birth control pills)
- how to learn not to go along with strangers

Some advice to parents:

- Plan for an independent life before your children leave home to live by themselves, in service housing or in a residential home. Then the feelings of emptiness won't be so great
- Help your children to make as many acquaintances outside the home as possible. This will teach them how to get along with other people. They will also learn how to take emotional setbacks, show that they can cope with them and bounce back again

Topics for Discussion

How do you regard sexuality among disabled and able-bodied adolescents? Is there any difference?

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Can Staff Contribute Towards a Better "Climate"?

Social welfare needs are met in many different ways when it comes to housing, transportation, aids for the disabled etc. But it suddenly gets much more complicated when we start talking about how a person as disabled can get help to enable him/her to have a sex life or a better sex life.

Sex life?

"The social worker pays me a visit. Society's contact person. She comes with her handbag and briefcase. Has a look around.
— What a nice place you have! Light and roomy. And you have flowers. And trees and grass outside. You must be happy here! She looks into the bathroom.
— Do you have difficulty getting into the bathtub? Are the handgrips located where they should be? How about the toilet? It seems a little low. Isn't it too low? You can have it changed if you like. You should be able to sit comfortably there too. The social worker makes notes on a pad while she talks.
— What do you think about the home help? How is it going with your working at home? Does the wheelchair work well? I have a few things I'd like to show you. She opens her bag. Shows some gadgets. Shows pictures of gadgets. Closes her bag. The social worker stands in the doorway.
— You live like royalty here. It's good when you can manage on your own. I'll be seeing you. Good-bye.
I feel anger welling up inside me. It suffocates me. Not until the door closes can I let go. Burning, silent words.
— What do you know? Eat! Go to the toilet! Is that all you can ask me about? Don't you think I have other natural needs as well? Why don't you ask me about them? Why? Why?
— My body isn't as much of a wreck as it looks. A lot of things in

it work. Heart, lungs. But also feelings, longings, drives. I need bodily nourishment. Food. Oxygen. But also human companionship, love, tenderness, lust. Those are also natural needs. Why don't you say anything about them? Why?"

(From Svensk Handikapptidskrift No. 1977:1 "Gemenskap — konflikt" ("Companionship and conflicts"))

No one is demanding that professionals within the social services or at institutions should function as some kind of "love army", i e as surrogate partners. What is needed is someone to talk to, someone who takes the disabled person's sexual needs seriously, who gives some advice on how to meet people and information on what the disabled person can and cannot do.

It happens that residents at institutions get disappointed in the staff and their families when their attempts to find some kind of sexual fulfilment are directly counteracted. They have, for example, noticed that attempts are made to separate them as soon as any emotional bonds are noticed. If there is a shortage of staff, it may sometimes be difficult to get assistance in getting ready for bed. This can sometimes also be used as an "excuse".

Reconsider Silent Agreements

It is important that the staff dare to discuss and clarify their own attitudes together. This may make it easier to encourage residents at institutions to seek contact with each other and with young people outside the institution.

Every human being should, regardless of any disabilities

- ▷ be given an opportunity to make outside acquaintances in order to be able to choose a partner
- ▷ obtain information on how he/she can function sexually with his/her particular disability

In the final analysis, people must be given control over their own lives. We are prepared to help them with this within many other areas.

The attitudes of the management of an institution influence to a great extent the opportunities for intimate relationships on the part of the residents. It is also a question of being open/closed to the community. Unwritten laws and silent agreements exist everywhere. What is important is how openly management and staff are prepared to discuss and reconsider their attitudes. At an institution for mentally retarded, for example, the residents thought that they could be punished in different ways if they had sexual relations. In actual fact, the staff were very positively disposed towards intimacy among the residents. Watertight barriers seemed to exist between the residents and the staff. Why? Simply because the staff had not explained what they thought to the residents. Openness between residents and staff is essential. Nor must we forget the integrity of the individual—in other words, we must respect the resident's private life, need to be alone and freedom from having to account for his or her sex life.

Topics for Discussion

Life together at institutions—what does it mean to you? Is it difficult—for whom? Why?

A Matter of Concern for All of Us

"A course should upset you. Otherwise it hasn't really served its purpose. You should go home with mixed feelings and feel that the subject is so important that you have to do something about it. And I do."

(Excerpt from letter after a course on sexuality and disability.)

Being able to cope with the sexual problems of the handicapped isn't something you learn merely by attending a course. Since it is often a question of changing one's atti-

tudes towards sexuality, it isn't something that can happen from one day to the next; it is a long-range effort.

We all have a responsibility when problems crop up.

"A lecture aroused my interest in disability and sexuality. It was a problem that I thought was really important to take up, something that had been pushed aside for much too long. And it didn't seem so difficult at the start, since I'd always considered myself so liberated and able to talk about sex freely. It turned out that I was quite wrong. It was one thing to talk about sex in the third person, but it is very seldom talked about in the first person."

"What I think feels most important right now is to awaken interest in the hospitals. Both among patients and nursing staff so that discussion groups can be formed to try to tackle this problem, which is much bigger than is commonly realized. It is important to get as many people involved as possible, for in numbers there is strength."

(From a special project, the Edsvik school for occupational therapists, spring term 1979.)

No professional group is better suited than another to provide information on sexuality and intimate relationships. The important thing is to be truly interested, to get your facts straight and to have a desire to do something positive for the good of others. In order to be able to talk about sexuality, people in all groups have to

- have a general knowledge of sexuality
- accept that a person with a disability may have a better sex life than they have themselves
- be able to accept other sexual activities than just intercourse and not transfer their own inhibitions to people with disabilities
- have discovered their own shortcomings when it comes to communicating perfectly with all people—and must be willing to refer to someone with a better ability to close contact with the individual
- train their imagination so that they can put themselves in a handicapped person's place and respect his/her right to be regarded as a whole person

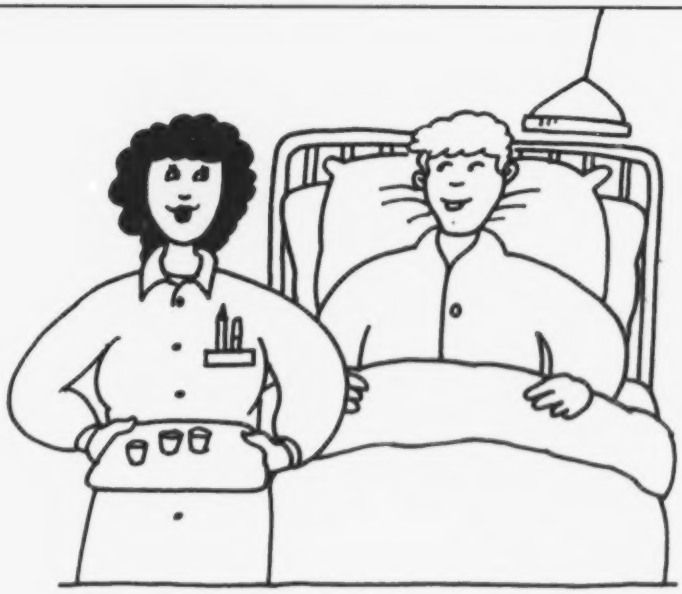
Another thing that mustn't be forgotten is the contact between members of handicap- and parents-organizations. It is important to give each other support and discuss sexual matters together. In study circles, the participants have often found it a liberating experience to have an opportunity to discuss sexuality and intimate relationships. "We could do with a lot more of this," is a common reaction.

How Do We Include Sexuality in Rehabilitation?

Awareness of one's own values and attitudes towards different forms of sexuality is essential when working to expand the opportunities for a functioning sexual life. A few more points within sexual rehabilitation are:

- to think of sexuality as something very broad and not just as sexual intercourse, coitus
- to give a person who has been injured as an adult back his/her self-confidence and to help him/her to discover his/her sexual identity
- to be positive and talk about possibilities instead of obstacles
- to take into consideration the individual's personal values and respect them, for example debut of sexual activities, upbringing, what value sexuality has in his/her life, which behaviour is preferred and what he/she is negatively disposed towards
- not to forget the partner and his/her values concerning sexuality

The management of the institution must have a positive attitude towards sexual rehabilitation. Those who work with these matters must receive the same encouragement and acknowledgment as those who work with other aspects of rehabilitation. Some ideas on what you can do to get discussions going at your place of work are presented below.



Topics for Discussion

How do you think the subject of relationships and sexuality should be approached:

- between doctor and patient
- between the patient and the staff category with which he/she has the best contact
- let sleeping dogs lie
- other options

How are these questions discussed at your place of work?

What support can we give to parents of children and adolescents with disabilities?

What support can we give to a newly handicapped person who wonders whether he or she will always have to live alone?

When someone in a family becomes disabled, this can lead to changes in different areas, for example:

- the relationship between the spouses

- the division of responsibilities in the home
- the children
- relationships with family and friends
- finances, working life
- opportunities for getting out etc

Which of these changes do you think it is most urgent to talk more about? Select them!

What can we do to make the changes easier? Which is the easiest one to handle? Describe what might be a good approach.

What tips would you who are disabled like to give the staff?

Start Study Circles and Discussion Groups!

Start a working group or a discussion group, perhaps in the form of a study circle, at your place of work, including representatives of all personnel categories. The group should not be too large, not more than ten persons. Don't forget that both residents/patients and family members can be included.

It is important that you prepare yourselves in the working group, are in agreement on what you wish to discuss (for example the questions brought up in this manual) and what you would like to get out of these sessions.

Try to agree on a common language so that you don't talk past each other! There is a tendency to talk in very general terms about sex and use technical terms instead of taking up concrete problems. Through techniques such as role-playing, you may find it easier to put yourself into different situations and understand your own and other people's feelings.

Topics for Discussion

Discuss some situations where you feel insecure and try to deal with them. (Continue thinking about these matters and talk to other people outside your group.)

Which of the following points are important for you to discuss? Choose the ones to which you attach the highest priority.

- Parents' attitude towards the sex life of disabled adolescents
- How it is to be a parent with a disability
- Opportunities to meet and daring to look for a partner
- The fear of losing a partner after becoming disabled
- Fertility. Pregnancy—childbirth. Contraception
- Increased activity on the part of the able-bodied or least disabled partner in the sexual interplay
- Other sexual activities than intercourse

Go through various kinds of study material concerning sexuality together and select what you would like to study more closely.

Read through different booklets and pamphlets and offer positive and negative criticism. You can get brochures at maternity centres, family planning counselling services and from organizations for sexual information.

Bear in mind in this context that you

- can never force your opinion on someone else, in either sexual or other matters
- mustn't raise false hopes
- give information based on facts and emphasize similarities between people with and without disabilities. Both groups have heard all too often about the differences
- try to create an open and positive atmosphere so that you can start working on whatever negative attitudes exist

We started like this!

We Wanted Greater Frankness . . .

We, who are staff members and at a boarding school for courses for physically disabled adolescents, started a study circle on sexuality. The headmaster and a teacher who teaches sexuality and intimate relations in an upper secondary school were the instructors.

We wanted factual information and we wanted to create greater frankness around sexual matters. By working on our own feelings and values, we wanted to make it easier to talk about sexuality and intimate relations.

During the first sessions, we made use of Åke Edfelt's book "Det handlar om dig" ("It concerns you") as a basis for discussion.

Many of us wanted to know more about the sexual dysfunctions associated with different disabilities and diseases. We wanted to find out what we could do in more concrete terms to make it easier for physically disabled adolescents to have a good sex life.

It took quite a long time (about five sessions) before we realized that we had to take time out to discuss our own attitudes. Until we did, we weren't ready to assimilate information on the sexual dysfunctions of the pupils.

During the sessions, we also got information on what the pupils learn in their sex education in school. It was valuable in enabling us to answer their questions.

The original plan was that we should disband the study circle after ten sessions. But we felt that the group had become a support in our work and that we had gained a group security that we needed. We decided to continue meeting once a month or so and to discuss matters that we felt were urgent.

We learned that it is important to proceed cautiously and let an atmosphere of mutual trust develop naturally in the group. Each individual must be permitted to give as much of himself/herself as he/she wants to.

Rehabilitation Patients Were Given Guidance in Relationships and Sexuality

At a rehabilitation home where persons with neurological diseases stay for an average of 4–6 weeks, study circles are held continuosly. The staff are welcome to participate, but so far they have taken very little advantage of this opportunity. The nurse and the social welfare officer at the home are the study circle leaders.

There are a total of five sessions that take up neurology, rehabilitation, social matters and sexuality. The session on sex and the disabled comes last in the series. The idea is that it takes until then for the participants to get to know each other well enough to enable these matters to be discussed.

The atmosphere among the patients and between patients and staff has become more open. Many people who thought from the start that they had "nothing to contribute" were gratified to find out that they had a great deal to give. Daring to talk about their problems has encouraged many patients to take a brighter view of their future.

Taken from an essay by K Hallgren: "Metoder att arbeta med samlevnad och handikapp" ("Methods of working with sexuality and disability").

How can we start a course at our place of work with staff/pupils?

Appoint two persons to be responsible for starting the course. It is often easier to get things going and have a say when you are two. Contact the head of instruction at the hospital, school etc. The librarian and the head of instruction can provide tips on literature. Check with the head of instruction whether anyone else has had a course or study circle in sexuality before. If so, get in touch with this person. Local educational associations can also help and can defray a portion of the cost of literature and instructors or an occasional outside speaker. Post and information leaflet on the notice board an propose cooperation with the staff in other departments.

Attend Courses and Arrange Lectures

Get in touch with the person who is in charge of instruction and has access to course catalogues at your place of work or contact an Institute for the Handicapped, where you can get help in arranging your own course or information on seminars on sexuality and the disabled. Discuss with a superior how to finance this type of activity.

It is also possible for family members to participate in courses and seminars. Contact the local and national organizations for the handicapped and educational associations to explore the possibility of obtaining financial support and help in starting courses.

It is also a good idea to arrange lectures. For example, you can invite a guest speaker to speak about different problems, solutions and possibilities.

The lecture should be followed by discussions in small groups. A follow-up session can then be held in the large group where any misunderstandings and other questions that have come up can be straightened out.

Lectures on sexuality without follow-up discussions are usually not very meaningful, since a change for the better requires that the whole group participate and take a stand on the different questions.

When Your Own Knowledge Isn't Enough

Discuss the questions that are of greatest urgency within your department/unit/school and find out who possesses what knowledge. Make it clear as to who is in charge of doing what.

- If no one in the department possesses sufficient knowledge, find out through the head of instruction whether anyone at the place of work has received instruction. Contact the person in question and ask him if he is willing to answer questions or provide information.
- Divide the books on sexuality and/or disability among yourselves and study the literature.
- Family counsellors, gynaecologists, organizations for the handicapped, the staff at youth outpatient units, urologists, neurologists, health centres, family planning units etc in your community can provide information. The department of neurology at your local hospital may, for example, be able to tell you whether a given disability in itself involves organic damage that can lead to an impairment of sexual functions. Explore the situation where you live.

We hope that this manual will inspire you to get started and work with the problems of sexuality among the persons who are disabled. This subject is so important and has been neglected for so long. Everyone is needed in this work.

But this work requires more than just enthusiasm; it also requires a willingness to put yourself in other people's place to see things from their point of view. Generosity is another important quality in your work. A generosity that is directed both inward towards your own group (staff or disabled) and outward towards the world around you.

Professionals who can provide you with informations in your community

Important telephonenumbers

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SEXUALITY AND DISABILITY

- a Matter that Concerns All of Us

Sexuality and disability—a matter that concerns all of us! By giving this title to our book, we wish to indicate how important this subject is—for all of us. We invite each and every one of you to give careful thought to and discuss your attitudes and values concerning sex and intimate interpersonal relationships. At the same time, we wish to give a greater practical content and meaning to the concept of sexuality for people with disabilities.

Misconceptions concerning sexuality and disability are not uncommon. With this book, we hope to be able to dispel many myths while at the same time providing some basic knowledge to make it easier to tackle these questions and start discussions and instruction.

The goal has been to put together a simple, general and easy-to-comprehend training manual that can be used in staff training courses, adult study circles, seminars and other educational settings.

The target groups are nursing teachers, student nurses, teachers and students at other schools that have contacts with disabled persons, staff at various kinds of institutions of care, people with desabilities and their families and loved ones etc.

The Swedish Institute for the Handicapped
Box 303, S-161 26 Bromma,
Sweden
Tel. int. + 46 8 87 91 40

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